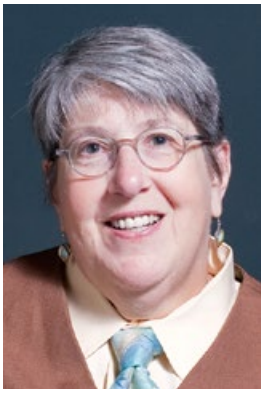
GMHC SEROZERO JUL/AUG 2014

# Mandatory Mail Order Pharmacies: A Bitter Pill to Swallow

*By Janet Weinberg, Interim CEO and Chief Operating Officer, GMHC*
*& The Honorable Letitia "Tish" James, New York City Public Advocate*

**MANY PEOPLE LIVING** in New York City know how frustrating it can be to receive a package in the mail. The redelivery notice asks you to be home when you're supposed to be at work. A birthday gift finally delivered to your apartment door gets stolen. Most chalk it up to life in the Big Apple. But what if that package is the prescription your mother needs to fight breast cancer, or the antiretrovirals that keep HIV at bay? Missing that package transforms an inconvenience into something dangerous to your health.



This is the crisis facing countless New Yorkers with life-threatening and chronic conditions — including cancer, lupus, HIV, multiple sclerosis, hemophilia, rheumatoid arthritis, and many others — who are required by the health insurance industry to use mail order pharmacies. The industry is exploiting a loophole in a law passed in 2011. The law was meant to ensure consumer choice, but instead it allows the insurance industry to compel New Yorkers to receive their prescriptions by mail. The law enables insurance companies to mandate unachievable "terms and conditions" on local pharmacies, preventing them from qualifying to fill prescriptions deemed "specialty" by the industry, even if they match the cost.

Janet Weinberg (top), Letitia James (above)

The result? Prescriptions are lost in the mail or stolen, requiring consumers to pay the full cost for replacements. Drug regimens are interrupted, which leads to resistance and more expensive treatment. Prescriptions that require refrigeration are left to spoil at the front door, and confidential health information is disclosed to neighbors who receive medications in error.

As an example, a GMHC client had a relationship with his local pharmacy for 30 years before being forced to use United Healthcare's mail order pharmacy, OptumRx. When Optum lost his HIV medication in the mail, a representative said that he'd either have to skip his HIV treatment for three weeks (until the next month's cycle) or pay over $1,000 for a new prescription. Another client, who was forced to use Empire Blue Cross' mail order pharmacy, now has to take eight days off from work per year to make sure he is home to receive his medications.

Insurance companies claim to offer individual exemptions, enabling the use of a local pharmacy. However, they do not provide consumers with transparent and adequate notice of how to apply. Often, exemptions are granted arbitrarily and only to those who have the time and health to work through a long and frustrating appeals process, with no guarantee of relief.

Mandatory mail order pharmacies are not only bad for public health; they're also bad for small businesses. Pharmacies, from local stores to the big chains, are being shut out by the health insurance companies and millions of dollars are directed out of state. The important community connection between a patient and her neighborhood pharmacist is replaced by an unfamiliar voice on the phone that has no relationship with patients, no incentive to ensure that medications arrive on time, and no accountability if a prescription is lost in the mail or stolen. In 2012, the Legislature and Governor ensured that State Medicaid enrollees were not forced to use mail order pharmacies. The law should be the same for all New Yorkers.

The New York City Public Advocate's Office, along with the New York City Council, is working with GMHC to raise awareness on this issue. One solution is New York's Anti-Mandatory Mail Order Pharmacy Bill. It enables New Yorkers, not the insurance industry, to choose whether to fill prescriptions by mail

or from a local pharmacy, as long as the pharmacy matches the average wholesale cost.

This bill enjoys bi-partisan support from a broad coalition of over 60 healthcare and patient advocacy organizations representing New Yorkers across the state. As the bill works its way through the state legislature, insurance companies can do the right thing by notifying all consumers about their right to request a hardship exemption and by laying out a clear process for obtaining it.

Twenty-nine years ago, GMHC launched AIDS Walk to engage the public on the growing AIDS epidemic. Since then, we have fought to protect and promote public health issues affecting all New Yorkers, including those living with HIV/AIDS. Now, as we walk to commemorate those we have lost and to show our collective resolve for fair public health policies, let's make sure all New Yorkers can choose to fill their lifesaving prescriptions by mail or at their local pharmacy, whichever is best for them and their loved ones.

## Releasing Health: I was Afraid I was Going to Die in the Cell

*By Alan Perez, founding member, GMHC's Action Center*

**IN 1990 I** was arrested for marijuana possession. I believe I was HIV positive at the time because I was getting sick, but I was not officially diagnosed until 2001. The judge sent me to Rikers Island — New York City's primary correctional facility — for 90 days. This was scary because I lost my apartment, I lost my job and I missed a lot of my college classes.

On my third day at Rikers, I got sick. I had diabetes and my blood sugar was up. I also had high blood pressure. I asked the correctional officer to take me to the hospital. They refused. They left me in the cell, where I had seizures.

At that time, I was afraid that I was going to die in the cell. I told the correctional officers that I wanted to see the doctor because I needed medication for diabetes and high blood pressure. They refused to take me. Eventually, they put a spoon in my mouth so that I wouldn't bite off my tongue. Finally, they took me to the hospital because they were scared that it would get worse. They called the ambulance.

In the hospital they had me handcuffed to the bed. I was uncomfortable because I had a catheter and I had to move my bowels in a pan. I was in the hospital for almost a week. The doctors said that I had to take care of my health. They said that my stress and diabetes could cause my liver to fail.

When I got back to prison, the other inmates started looking at me weird and calling me names like "faggot," but I didn't pay them any mind. I didn't get along with the other inmates most of the time because I was afraid that they might hurt me. I thought they were going to beat me up because I was HIV positive.

There was one inmate who wanted to have sex with me. I told him no because I thought I was HIV positive and I didn't want to infect him. I told him that I could be his friend and give him advice on how to not get infected and told him to get tested.

Otherwise, I was isolated in my room all of the time. I never came out of my cell, not even to watch TV or to eat. I lost a lot of weight in prison because I was sick and because I was afraid to be with the other inmates in the cafeteria. The guards noticed that I wasn't eating and they didn't do anything. It was lonely because I had no visitors. No family members called me. They didn't write me letters.

Another problem was that it took a long time to get my medication for HIV and for my diabetes. Every time I went to see the doctor for my medication I had to wait in line. Once, my name was not on the list for the medication and I had to wait. When they finally did have my medication, they only had three of the four I needed. Other inmates didn't have their medications available as well.

Before they released me, I had to go to court. The judge said that I had to go to rehab and detox for marijuana and cocaine possession. He gave me a program to go to so I could clean myself up. I've been clean now for 20 years.

When I came out of prison, my mother passed away and I couldn't be at the funeral because I had to be at rehab. The judge told me that I had to stay out of trouble. He didn't want me to hang out with people that I used to hang out and do drugs with.

When I came home from rehab, all my friends and family were happy to see me. They said they would support me in every way they could for me to stay clean and not go back to prison.

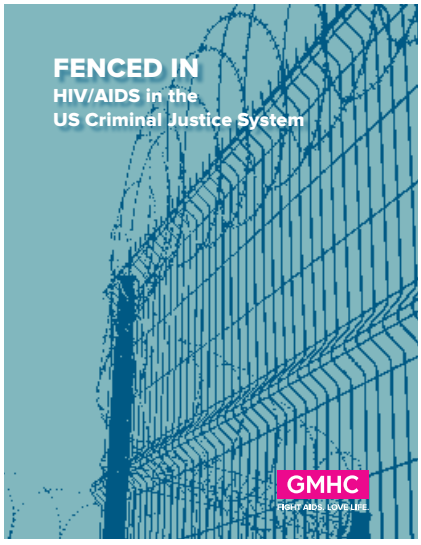
It was a hell of a ride being in prison. I learned my lesson and don't want to go back. I have many things to do out here and I want to get my life back together.

# Excerpts from "Fenced In: HIV/AIDS in the US Criminal Justice System"

*by Elizabeth Lovinger*

## HIV in U.S. Correctional Facilities

There are approximately 2.2 million people in jail or prison in the United States. According to the Bureau of Justice Statistics (BJS), about 1.5% of all inmates in state and federal prisons have HIV or AIDS (21,987 persons). That percentage is four times higher than the prevalence rate of HIV in the general population. The BJS reports that Florida (3,626), New York (3,500), and Texas (2,450) have the largest number of inmates who are HIV-positive. The BJS also reports that the rate of infection for female inmates (1.9%) is even higher than that of their male counterparts (1.5%). The primary routes of transmission are suspected to be unprotected sexual contact and intravenous drug use (IDU), but precise data on infection and transmission are not available. While numbers remain high for HIV prevalence in prisons, the data may underestimate both HIV prevalence and incidence due to existing stigma and fear. This stigma not only leads to nondisclosure of HIV-positive status, but also places prisoners at an elevated risk of infection.

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## Healthcare in Prisons and Jails

The fight for proper care and treatment in prisons has been long and difficult and, despite some progress over the years, enormous gaps remain. HIV, tuberculosis and hepatitis are among the most common infectious diseases in U.S. prisons. The CDC reports that up to 41% of inmates have ever been diagnosed with Hepatitis C virus (HCV) and up to 35% are chronically infected. In the un-institutionalized population, HCV prevalence is 1–1.5%.

Disparities in HIV and HCV infection between incarcerated and non-incarcerated populations demonstrate inadequate access to care and treatment. HCV prevalence is also significant because it is linked to HIV. Both infections can be transmitted through unprotected sexual contact and injection drug use. Additionally, HIV-positive individuals are disproportionately affected by viral hepatitis; about one-third of HIV-infected persons are co-infected with hepatitis B virus (HBV) or HCV.

The onset of the HIV epidemic, coupled with a political and legislative climate that was hostile toward prisoner health, led to deterioration in health care. Prisoners increasingly faced obstacles to HIV medical care in correctional facilities. In November 1981, the first prisoner in New York State was confirmed to have died from AIDS-related complications. By the early 1990s, two-thirds of all deaths of incarcerated persons in New York were AIDS-related. Some 7.4% of inmates in Northeast state prisons were known to be HIV-positive in 1993, a 22% increase from two years prior. The number of inmates in state and federal prisons with an AIDS diagnosis increased 124% from 1,682 in 1991 to 3,765 in 1993.

## Condom Access

Although the prevalence of high-risk sexual behaviors and sexual assault demonstrate the need for proven HIV prevention methods in correctional facilities, only five county jail systems (New York, Philadelphia, San Francisco, Los Angeles, and Washington, DC) and two state prison systems (Vermont and Mississippi) allow prisoners access to condoms. This represents less than 1% of all U.S. jails and prisons. Correct and consistent use of condoms reduces the risk of sexually transmitted infections (STIs) and HIV transmission. Condoms remain the single-most effective prevention intervention and will go a long way towards reducing HIV transmission and other STIs in the corrections system.

## HIV Education and Testing

Other than limited knowledge about HIV, specific policies within prisons serve as major obstacles to successful HIV testing. HIV testing strategies vary considerably among correctional facilities and include mandatory, voluntary, and opt-out testing. However, structural barriers largely prevent prisoners from getting tested. Fear of discrimination, lack of confidentiality, and stigmatization of IDU and MSM behaviors hinder access to prevention services and HIV testing and continue to fuel the epidemic in the corrections system.

In order to address these barriers and increase HIV screening, the CDC has recommended routine opt-out HIV testing in all health care settings, including prisons and jails. Under these recommendations, HIV screening is made available as part of the standard medical evaluation and is performed unless the patient declines. The CDC recommendations also include annual testing for persons at high risk for HIV infection, but unfortunately do not require accompanying prevention counseling.

***Black prisoners are 3.5 times more likely than white inmates, and 2.5 times more likely than Latino inmates, to die from AIDS-related causes.***

### The JUSTICE Act

Without uniform prevention, testing, and treatment programs, incarcerated persons living with HIV and/or other STIs can unknowingly infect others. Often left untreated, incarcerated persons with STIs are frequently in the more advanced stages of their disease, and once released can be even more costly for the public health system to treat. One outcome of the lack of a coordinated response to HIV is that among confirmed AIDS cases in prisons, racial minorities account for the majority. Black prisoners are 3.5 times more likely than white inmates, and 2.5 times more likely than Latino inmates, to die from AIDS-related causes.

In August 2011, Representative Barbara Lee (D-CA) introduced H.R. 2704, The Justice for the Unprotected against Sexually Transmitted Infections among the Confined and Exposed (JUSTICE) Act. This legislation would allow prisons to provide condoms to incarcerated individuals. The JUSTICE Act also calls for automatic reinstatement or re-enrollment in Medicaid for people who test positive for HIV before reentering communities. This action is of tremendous importance to public health since it would provide a comprehensive response to the spread of sexually transmitted infections in correctional facilities.

### Stop AIDS in Prison Act

The Stop AIDS in Prison Act, sponsored by Representative Maxine Waters (D-CA), addresses comprehensive HIV care and prevention in federal prisons on a structural level. The bill calls upon the Bureau of Prisons to take 11 concrete steps to combat HIV in prison, promote awareness, and improve medical care. All testing and medical care would be required to be strictly confidential, with penalties for any breach of confidentiality.

The Act would include HIV testing as a medical service provided with consent during intake and within three months prior to release. Testing would also be provided upon request once per year, or following high-risk exposure or upon pregnancy. Prison personnel would be instructed to encourage inmates who might be at high risk for HIV infection to get tested, and would be prohibited from using any request for testing as evidence of misconduct. Those who tested positive for HIV would have the option of "partner notification services." Inmates would be able to refuse testing at any time, for any reason, without penalty.

Inmates would also be entitled to comprehensive medical care in a timely fashion, with confidential consultations about managing the virus. Upon release, prisons would need to provide information about where to receive treatment and care in the community, as well as 30 days' worth of medication.

In addition, prisons would need to provide educational opportunities for inmates about modes of HIV transmission. This would involve working with a number of organizations, agencies, and well-informed inmates to provide culturally competent and accessible presentations, written materials and audio-visual resources in multiple languages. Within one year, the Bureau of Prisons would need to report to Congress on its policies to enforce the above provisions. Within two years, and every year after, it would also need to report incidence rates of STIs and intravenous drug use.

# GMHC Action Center Interview: A Report from AIDSWatch 2014

*by Sarah Glasser, Community Coordinator and AVODAH Fellow, GMHC*

At the end of April 2014, GMHC Action Center members and staff participated in AIDSWatch 2014, the nation's largest annual HIV-focused grassroots advocacy event in Washington, D.C. AIDSWatch brought together over 300 grassroots activists from 27 states to call on Congress to support efforts to end the HIV/AIDS epidemic. AIDSWatch connected activists to meetings with 222 Congressional offices focused on seven policy priorities, which included the Ryan White Program, the Affordable Care Act, stable housing for people with HIV, and federal funding for HIV programs.

In addition to supporting client attendance for the big lobby day on Tuesday, April 29th, GMHC provided scholarships for two Action Center members, David Brock and Marc Antonio Chen, to attend a training session on Monday morning that included opening remarks from Douglas M. Brooks, the new and first openly HIV-positive Director of the White House's Office of National AIDS Policy (ONAP).

David was particularly interested in legislation focused on providing comprehensive sex and HIV education in schools to prevent the continued spread of HIV among youth. Marc was focused on Housing Opportunities for People With AIDS (HOPWA) legislation because of the critical role of stable housing in treatment adherence for people living with HIV/AIDS.

Marc was also interested in issues that were not included in the AIDSWatch agenda. "I found it interesting that the organizers didn't focus on sex workers and the arrests of sex workers for carrying condoms," he said. "We need more funding for condoms and sex education."

In New York State, police officers have been confiscating condoms to use as evidence in sex work trials, which is a serious threat to public health because it has a chilling effect on condom usage, particularly among populations at highest risk of infection.

AIDSWatch is powerful because it builds community among people living with HIV/AIDS and provides them the opportunity to learn how to share their personal stories and experiences. It then empowers them to use those stories to advocate for change in meetings with legislators and policymakers.

As David, who lives in New York City, shared, "It was amazing for me to hear from people in other states, especially the Southern states, on homelessness and housing. That touched me the most. There was a lady from a southern state who talked about [HIV-positive] people living in the woods."

Marc and David were also impressed by the diversity of people who attended.

"Women were a big part of the conference this year. Very little funding is going to women or transgender people living with HIV," David said. "I don't know why it has taken so long for them to recognize women, because as long as men have had HIV, women have as well. Also, people who are transgender are standing up more for themselves."

From left to right: Ron Regins, Jason Hill, David Brock, Marc Antonio Chen (behind David), Monté Clarke (far back), and Alan Perez in GMHC's Action Center meeting room, debriefing after a long and successful advocacy day in Washington, D.C.

Marc agreed, stating that AIDSWatch had "a great balance of men, women and people from all generations. It was great networking with people from around the United States."

On Tuesday morning, a bus full of GMHC Action Center members and other activists from AIDS Service Center, Harlem United and Housing Works arrived and joined Marc and David. Action Center founding member Alan Perez noted that "there was a lot of camaraderie" on the bus.

"We know each other and all the other activists are from the same area," added Monté Clarke. "We're a nucleus."

Unfortunately, they arrived to heavy rain.

"With all the rain and stuff, we did really well," said Marc. "We were troopers. The Rally to End

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AIDS was cancelled, but the lobbying continued despite the rain."

The Action Center members' first meeting was with Congressman Charles B. Rangel, who represents Upper Manhattan and parts of the Bronx. They were particularly excited that his staff were knowledgeable about HIV/AIDS-related policies, including syringe access and housing.

"It was amazing," shared Jason Hill. "I was impressed by his chief-of-staff. She was well-informed and interested, so much so that someone else from the office came over and started asking questions."

"It was a privilege meeting with such a sage and august staff member," added Ron Regins. "Congressman Rangel is very powerful. He runs the House Ways & Means Committee."

Action Center members then went to meet with Representative Yvette Clarke, whose district is in the center of Brooklyn. They discussed literacy, sex education, housing and healthcare services.

"She knew a lot about comprehensive care," David added. "She was concerned about getting more comprehensive care in her district."

Comprehensive care is valuable for people living with HIV/AIDS because it consolidates all necessary medical services in one area and allows care practitioners to communicate and collaborate.

Monté reflected, "It was a very wonderful meeting. Congresswoman Clarke is the greatest lady. She kept saying, 'Yes, yes, I'm on that committee, I introduced that legislation.' She was the type of representative I would want in my district. She was on top of it. It was like talking to an aunt."

Ron smiled, adding, "She was very attentive, very focused. She knew of Gay Men's Health Crisis and she was very social. She was totally connected. We can count on her to be an ally."

Next on the agenda was a meeting with staff from Congressman Jerrold Nadler's office, who represents some areas in Manhattan and Brooklyn. However, two Action Center members were missing.

"At this point, Monté and I got lost," Ron said. "We went to the wrong building."

The capital area is incredibly confusing and in the pouring rain it was hard to tell the buildings apart. Ron and Monté, wet from the rain but smiling, eventually found their way to the meeting.

According to Marc, "Congressman Nadler has been dynamic with immigrant rights and everything we care about. He's very supportive, much like Thomas Duane [from the New York State Senate] was."

The last meeting was with staff from Congressman Jose Serrano's office, who represents neighborhoods in the Bronx.

Alan reflected, "Jaime Guttierez, a former GMHC staff member who volunteered to come to AIDSWatch with us, was magnificent. He deserves a thank you. He really discussed Ryan White well."

Ron added that he was impressed with Congressman Serrano's Chief-of-Staff Adam Alpert. "Adam was excellent, concerned and knowledgeable. Having visited with him was a plus. He was particularly interested in HIV criminalization. Congressman Serrano even met with us and took a picture."

Finally, after a busy day, the Action Center members walked back to the bus through the tunnels under the capital and prepared for the long ride home.

"This was a very good AIDSWatch," reflected David. "It was a good turnout. I feel honored that I was there for both days."

"Me too," Marc added.

"I hope it happens again next year," concluded David.

Ron summed up his thoughts on AIDSWatch: "I've been on a lot of trips. We've had a lot of successes and a very good year. The Action Center seems to rise to every occasion and we are stronger each year. Right now we are a very cohesive unit, putting the issues of people living with HIV/AIDS first and foremost."